# Iowa Autism Council Meeting October 12, 2011 Meeting notes taken Beth Buehler-Sapp Meeting Minutes summarized by Toni Merfeld

Present: Sue Baker, Josh Cobbs, Danielle Sharpe, Jeff Gitchel, Rachel Heiss, Steve Muller, Robin Sampson, Debra Waldron, Charles Wadle, Susan Smith, Bara Stineman, Patrick (Casey) Westoff, Becky Harker, and Beth Buehler-Sapp

Absent: Katherine Byers, Karn Johansen, Jan Turbes, Ruth Allison, Jeanne Prickett, Jim Mumford, Marty Ikeda, Toni Merfeld, and Karalyn Kuhns.

Guests: Lin Nibbelink, Iowa Department of Human Services (sub for Karalyn Kuhns) Dr. Bob Stensrud and Mike Couvillion from Drake University

Josh called the meeting to order and asked folks who don't access e-mail at all or just occasionally to let us know so we can call those members and mail materials to them when needed. Rachel Heiss stated that she only has e-mail access on Monday-Friday (office). Becky Harker informed the group that she doesn't read e-mails closely.

Josh informed the group that the CARA (Combating Autism Reauthorization Act) just renewed for another 3 years due to legislation signed by President Obama.

Dr. Bob Stensrud and Mike Couvillion talked about the results of the recent survey conducted with parents, caregivers, and individuals living with Autism Spectrum Disorders. The purposes of the survey were to begin to understand the sampling of geographical location of students, sampling of how many students were in the system, and to what level parents were satisfied with their student(s) education.

The survey was completed by 233 respondents of which about 140 of them included comments. Sue Baker questioned whether the comments could be categorized? Dr. Stensrud said this would be difficult due to the variant satisfaction level of respondents. He stated "Satisfaction has everything to do with the expectations you go in with." The survey is intended to help families understand "What to expect?" and "How to Advocate". So many comments provide during the survey process indicated that lots of people weren't aware of choices potentially available to them.

Sue pointed out generally folks don't recognize the difference between services vs. Individualized interventions. Josh stated he would, like for Dr. Stensrud to make recommendations for next steps. Dr. Stensrud senses that "Some parents shop around for a diagnosis." Robin Sampson concurred with this thought due to the fact that service are often client-eligible based on a diagnosis and therefore many people strive to get this.

Dr. Stensrud stated "He would like to know who every kid in the state is with Autism and be able to talk with their parents. Sue Baker mentioned that we weren't able to access

information from the AEA's and PEC's this time but that attempting to do this in a timely manner next go-round of survey gathering is very important.

Josh mentioned that once the website is available (which is anticipated soon) that this will provide more options for folks to access information. He prompted Josh to remind members that "Everybody thinks everybody has an agenda." This is essentially true as most everything is guided by goals or desired outcomes. One noted aspect of the survey was that a respondent couldn't advance to the next question unless they answered the previous question.

Rachel Heiss said that often a person will receive services and know the agencies name and the city/town name but not the identity of the individual who provided the services. Sometimes conversely they may remember who the specific person who provided services was but not the name of the provider agency. Dr. Stensrud theorized that the longer a person had a diagnosis the greater their level of satisfaction seemed to be.

Steve Muller stated that he perceives that "Expectation drives Satisfaction." People often don't know what to expect or even all of the options available to them and are therefore satisfied.

Providers who are affiliated with an establishment or any kind seem to be less trusted by Persons receiving services as they often perceive there is an element of collusion or sticking together aspect. i.e., If a school doesn't believe a child needs something and someone comes in to make an assessment and they are from the AEA affiliated with the school, the child's parent often may not feel this was an objective process or that it is tainted.

Josh stated that even though someone has a diagnosis they may never get on a waiver. "It's like espionage trying to get on a waiver.

Jeff Gitchel asked the question, "Do we have any sense of how the regional services are going to change after the redesign?" "Right now with 99 counties going into 4 regions you could have a structure a lot easier to navigate."

Lynn Nibbelink, (guest from DHS) stated "She thinks this time the redesign is for real."

Debra Waldron stated "She's not sure the regional structure will be what the children's structure will look like. The children's aspect needs to be more on a child's needs basis rather than for just adults due to the dramatic difference between children's and adult's systems.

Josh pointed out that the complexity of the process is often problematic, for example, he was approached 3 times at a conference and asked "Why are we obstructing folks from getting a waiver?" Josh reminded the council that when it comes to insurance regulation the 28-32% of all insurance is state regulated which means 68-72% of all insurance is federally regulated and this makes a dramatic difference. Also, ADA services are provided by some employers through insurance coverage.

Sue posed the question "How do we find out who has accessed services?" Thoughts heard are that this would have to be gotten through the insurance and that as with the recent autism survey we designed there would need to be answers accessed by category and anonymity would have to be maintained.

Dr. Rachel Heiss shared that based on a recent survey that there are 46 residents per 1 provider per capita and that based on stats for services needed that more money in the health care industry needs to go towards the availability of psychologists. Therefore, as a state all areas would be considered underserved with the exception of Des Moines, Cedar Rapids, and Iowa City.

Program s are being implemented in the educational system whereby if a students education is pad for or assisted and a person interns in these less populated areas that it sis conditional that upon graduation that they stay in these areas.

Susan Smith stated "It's important to help parents know not only what's available but to provide them with guidance about what's effective."

Sue Baker agreed and stated, "Parents are clamoring for where they can go to access information, etc." There along continues to be discussion as to whether the website will only provide information or what a place where folks can post comments.

The example of the PACER Center was discussed as this is a facility that used federal dollars for professional development services with regard to Transition, Employent, and High Expectations.

The four sub-committees met and agreed upon th following priorities:

#### **Financing of Care sub-committee:**

- 1. Review and expansion of current law.
- 2. Current Redesign
  - a. Make-Up (Clinical Mental Health Providers)
  - b. Child Psychology Representation
  - c. Should be functionl based assessment rather than just an IQ or age based assessment.
- 3. Residential
  - a. Expense
  - b. Small
  - c. Community Based

#### 4. Value with funding.

#### **Further notes:**

few going through BCBA credentialing due to legislation. We need to be able to access this insurance to cover remaining 33% not accessing funding. We need to see the people not just the dollars regarding this change in MH redesign. Example of respite waiver hours, and this committee covers public and private supports and need to be connected to broader activities. Info net and a survey for people to respond to some of the recommendations. We can query if parents are participation in insurance legislation...some states can tell us who did it. They don't have to give it to us. But Chuck says won't get it through the state, probably. We can ask through the state..how much has it cost us...aggregate. One reason we have problems is that there is turnover. Cost argument should be over. This may create jobs, who are providers of service due to this legislation. Even at private pay or medical co pay, some parents don't want to pay, also have to drive to get this service. Rachel says Legislation is concerned about capacity, due to number of psychologists (want more). One of the problems, three internships available in Iowa. So few psychologist are underserved except DM, IC, and Cr. Post doc programs, can't get paid internship before PhD, there has been set uuup programs to serve rural psychologists and they have too stay in rural areas. Six psychologists have gone through this and there are not enough providers. Susan: what services are available but we also need effectiveness data to share with them (guidance) or some tool if I have this much money where do I want to put it.

#### **Education sub-committee:**

- 1. Follow-Up Survey
- 2. Parent Information
- 3. Improve all Levels of Transitions.
- 4. Do we have enough child psychiatry providers?

#### **Further Notes:**

Work with the survey and with Marty's data, too. How do we provide effective services. All levels but we have school aged targeted, and see how resources are allocated. Replicate where services are going well, maybe strategy, funding, classroom set up.

#### **Web-Site sub committee:**

## **Background information about for site**

- Not much cost for Google sites URL; can the site be monitored quarterly?
- Subcommittee members: could periodically check links work
- Monitor traffic to get additional funding: can their be a counter?
- Access by newly diagnosed parent should be no problem
- Audience: parents/family; community members, professionals

### **Overall Guidelines for the site**

- 1. Focus on Iowa based services—No editorial point of view
- 2. Reference IAC agenda, (agenda and recommendations are available at Iowa Department of Education site
- 3. Can we have a search function-can we use key words—This helps to determine duplication of links
- 4. Standard for Evidence Based Practice is the National Autism Center & the National Professional Development Center with science behind interventions. These interventions can be classified into three age groups: birth-toddlers; schools aged, and transitioning adolescent and adult
- 5. Do we want a disclaimer: It should be available in all three age groups. We don't endorse anyone or any specific intervention; do we need legal supports to review the site (see Ohio site disclaimer and agree we can add it to our site)

# Guidelines for State Agency listings on the left and other site functions

- Can download a service provider (need clarification as to what this means)
- Can we find Ohio's process to approve private/not for profit agencies—and include for the IAC website committee to review when someone wants to be added, but is not a statewide agency
- Ask Homestead to complete form, as they are not state-wide
- Camp sites can be added to the services
- Add sentences to let newcomers list their services on the special request form—website committee issues confirmation back to that service provider
- Google Docs public access—contact Janell Bradhurst at DE for more information
- Blog/Chat room: No one to chat/observe (for civility)
  -Not our function
- Facebook/Twitter-May also need monitoring—No resources to monitor/manage so the site will not be available on Facebook or Twitter at this time
- Perception or validation check on IAC recommendations from the public. Can the public inquirer tell how much they agree or disagree with a recommendation using a survey monkey?

Further Notes:

timelines may be too agreesive. Parents want something about how to start a process. Just diagnosed, what do I do. Adult services are beginning to what do I do. Katie: wordsmither. Find what they need and call or e-mail. We need to think of setting up facebook and twitter account to publicize the meeting. More ways to get them to interact with us: down the road.

#### **Adolescent and Adult Services sub committee:**

- 1. Expand I-PART to align with regional based system, adequately fund with waiver expansion (proposed to end 12/3/11) current grant funds.
- 2. The ASD 2012 Employment Symposium.
  Employment First APSE Government Group Vocational Rehabilitation
- 3. Other State Initiatives
- 4. Sub-Committee work on best practices: Let's look at what other states have done and what they've learned.

#### **Further Notes:**

Casey and Susan are chairs. Employment First could come and talk about a broad vision about transition and adult services. We have something happening at the beginning of the year (Suzanne something), Pacer Center, MN modules on transition, higher expectations, and one other topic. One for post secondary education. Get some discussion about it. Http: autism internet modules.org notes two topics on adults with ASD and supporting employment

Becky Harker mentioned getting a grant that would fund partnerships for systems change for youth with developmental disabilities. This will hopefully provide an array of options for people to develop the skills and opportunities to work. Families may have expectations but are nor taking the steps needed along the way.

Steve Muller stated that one of the best ways to possibly maximize results is to promote our core beliefs and align our efforts with other entities who have the same or similar core beliefs.

Steve made a motion to communicate to the re-design council our support of the continuance of I-PART and to encourage them to consider this within the Redesign process. Jeff Gitchel seconded this motion and a vote was called for. With twelve voting members being present

This passed with an 11 vote in favor with 1 voting member (Chuck Wadle) abstaining.

Josh Cobbs made a motion to adjou	ırn the meeting and Jeff G	itchel seconded the motion.